Enhancing Well-Being in Older Adults Living with Dementia

G. Allen Power, MD, FACP
Eden Mentor – St. John's Home, Rochester, NY
Indiana Healthcare Leadership Conference
April 9th, 2013

Disclosure of Commercial Interests

- Board member and educator/consultant for The Eden Alternative, Inc. (not-for-profit culture change organization)
- No pharmaceutical affiliations or other commercial interests

Objective

To change your minds about people whose minds have changed

Perspectives

"The only true voyage of discovery . . .would be not to visit strange lands, but to possess other eyes, to behold the universe through the eyes of another, of a hundred others, to behold the hundred universes that each of them beholds, that each of them is . . ."

- Marcel Proust

U.S. Antipsychotic Prescriptions Since 2000

- U.S. sales, (2000→2011): *$5.4 billion→$12.6 billion*
- Prescriptions, (2000→2011): *29.9 million→54 million (~2.2 million Americans have schizophrenia)*
- 29% of prescriptions dispensed by LTC pharmacies in 2011
- *Overall, 25.2% of people in US nursing homes are taking antipsychotics (>1/3 with a diagnosis of dementia)*
- *Medicaid spends more money on antipsychotics than it does on (1) antibiotics or (2) heart medications*

Big Secret #1:

Antipsychotic overuse is not an American problem!

- Denmark (2003) – 28%
- Australia (2003) – 28%
- Eastern Austria (2012) – 46%
- Canada (1993-2002) – 35% increase (with a cost increase of 749%!)
- Similar data from other countries (2011 study of >4000 care home residents in 8 European countries→26.4%)
- Worldwide, in most industrialized nations, with a diagnosis of dementia: ~35-40%

Behavioral Expressions in Dementia Do Drugs Work?

- Studies show that, at best, fewer than 1 in 5 people show improvement
  Karlawish, J (2006). NEJM 355(15), 1604-1606.
- Virtually all positive studies have been sponsored by the companies making the pills
- Many flaws in published studies
- Two recent independent studies showed little or no benefit

Sink et al. (2005), JAMA 293(5): 596-608; Schneider et al. (2006), NEJM 355(15): 1525-1538.

Risks of antipsychotic drugs

- Sedation, lethargy
- Gait disturbance, falls
- Rigidity and other movement disorders
- Constipation, poor intake
- Weight gain
- Elevated blood sugar
- Increased risk of pneumonia
- Increased risk of stroke
- **Ballard et al. (2009): *Double* mortality rate. At least 18 studies now show increased mortality, (avg. increase ~60-70%)** *Lancet Neurology 8(2): 152-157*

Big Secret #2:

Antipsychotic overuse is not a nursing home problem!

- Nursing home data can be tracked, so they get all the attention
- Limited data suggests the magnitude of the problem may be even greater in the community
  - Rhee, et al. (New England – 19%)
  - Kolanowski, et al. (SE US) – 27%
- 2007 St. John's audit
- At least 4 out 5 people with dementia live outside nursing homes; therefore, there may be *a million Americans* using antipsychotic drugs in the community (vs. ~400,000 in nursing homes)
- Our approach to dementia reflects more universal *societal* attitudes

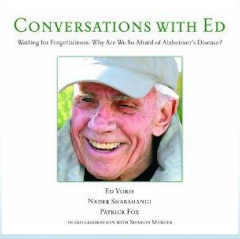
The Biomedical Model of Dementia

- Described as a constellation of degenerative diseases of the brain
- Viewed as mostly progressive, incurable
- Focused on loss, deficit-based
- Policy heavily focused on the costs and burdens of care
- Most funds directed at drug research

Biomedical "Fallout"…

- Looks almost exclusively to drug therapy to provide well-being
- Research largely ignores the subjective experience of the person living with the disease
- Quick to stigmatize ("The long goodbye", "fading away")
- Quick to disempower individuals
- Creates institutional, disease-based approaches to care
- Sees distress primarily as a manifestation of disease

Illustrative Example:



So…
Why Do We Follow this Model??

- Are we bad people?? ***No!***
- Are we lazy? ***No!***
- Are we stupid? ***No!***
- Are we uncaring? ***No!***

- Do we have a paradigm for viewing dementia? ***Yes!!***

"Instead of thinking outside the box, get rid of the box."

A New Model
(Inspired by the True Experts…)




A New Definition

"Dementia is a shift in the way a person experiences the world around her/him."

Where This "Road" Leads…

- From fatal disease to changing abilities
- The subjective experience is critical!
- From psychotropic medications to "ramps"
- A path to continued growth
- An acceptance of the "new normal"
- The end of trying to change a person back to who he/she was
- A directive to help fulfill universal human needs
- A challenge to our biomedical interpretations of distress
- A challenge to many of our long-accepted care practices

In Other Words;;;

Everything changes!

Perspectives…

Does cough syrup cure pneumonia?

Behavioral expressions are the ***symptom,*** *not the* ***problem!***

Big Secrets # 3 & 4:

- Our primary goal is ***not*** to reduce antipsychotic drugs!
- Our primary goal is *not even* to reduce distress!!

Primary Goal: Create Well-being

- **Identity**
- **Connectedness**
- **Security**
- **Autonomy**
- **Meaning**
- **Growth**
- **Joy**

(*"Wandering" example…)*

MAREP (Ontario, Canada) Living Life through Leisure Team

- Being Me
- Being With
- Seeking Freedom
- Finding Balance
- Making a Difference
- Growing and Developing
- Having Fun

Leisure – Well-Being Alignment

- Being Me ← → Identity
- Being With ← → Connectedness
- Seeking Freedom ← → Autonomy
- Finding Balance ← → Security
- Making a Difference ← → Meaning
- Growing and Developing ← → Growth
- Having Fun ← → Joy

So what does this have to do with culture change??

Everything!!

Why it matters

- No matter what new philosophy of care we embrace, if you bring it into an institution, the institution will kill it, every time!
- We need a pathway to *operationalize* the philosophy—to ingrain it into the fabric of our daily processes, policies and procedures.
- That pathway is *culture change*.

Big Secret #5:

Why "Non-Pharmacologic Interventions" Don't Work!

- Discrete activities, often without underlying meaning for the individual
- Not person-directed
- Not tied into domains of well-being
- Treated like doses of pills
- ***Superimposed upon the usual care environment***

Transformational Models of Care

Transformation

- **Physical:** Living environments that support the values of home and support the domains of well-being.
- **Operational:** How decisions are made that affect the elders, fostering empowerment, how communication occurs and conflict is resolved, creation of care partnerships, job descriptions and performance measures, etc., etc.
- **Personal**: Both *intra-personal* (how we see people living with dementia) and *inter-personal* (how we interact with and support them).

Big Secret #6:

Culture change is for everyone!!

- Nursing homes
- Medical community
- Federal and State regulators
- Reimbursement mechanisms
- Families and community

Creating the *Context* for an Experiential Approach

- Positive view of aging
- Seeing the whole person
- Looking through the person's eyes
- Being centered and present in the moment
- Communication and facilitation skills
- Looking beyond the words
- *Turning our backs on the "behavior", and finding the "ramps" to well-being*

Experiential Approach to Decoding Distress

Dementia is a condition in which a person's ability to maintain her/his well-being becomes compromised

General Approach

- Medical Audit (not always necessary)
- Environmental Audit
- **Experiential Audit**

Experiential Audit

- Distress as unmet needs
- Life history, job, hobbies, activity patterns…
- Role play, see through his / her eyes
- Look for meaning in behavioral expression
- Look at well-being domains

Experiential Audit: Preparation

Jane Verity's *Spark of Life* steps:

- **Shift your focus**
  Begins with a concerted effort to move from our own perspective and see the world through the eyes of another
- **Share your heart**
  Look into the heart of another, without judgment
- **Shine your light**
  Use your insights to find the unmet need or environmental mismatch

Experiential Audit

Using Well-being Domains

- **Identity** *(Is my story known and understood by my care partners?)*
- **Security** *(Do I feel safe in my surroundings and do I trust those who provide my care?)*
- **Connectedness** *(Do I know my care partners? Do I feel like I belong in my living space?)*
- **Autonomy** *(Do I have opportunities for choice and control throughout the day?)*
- **Meaning** *(Are the daily activities meaningful to me? Are my self-esteem and ability to care for others supported?)*
- **Growth** *(Do I have opportunities to experience life in all its variety and to engage creatively with the world?)*
- **Joy** *(Is life celebrated with me? Am I loved?)*

Filling the Glasses

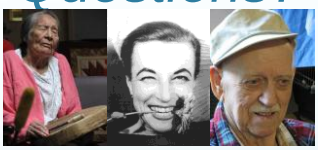
True Stories

Looking beyond the words…

"When we care for an elder, we care for that part of ourselves that will someday grow old."

- Dr. Nader Shabahangi

Thank you!
Questions?



apower@stjohnsliving.org
www.alpower.net